

Peer support for people with mental illness

Suporte interpares na doença mental

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Abstract

Background: Peer support is a mutual aid system based on the belief that someone who faced/overcome adversity can provide support, encouragement and guidance to those who experience similar situations. **Objective:** To conduct a systematic review that describes this concept and characterizes peer supporters, its practice and efficacy. **Method:** Research on ISI Web of Science, EBSCO Psychology and Behavioral Sciences Collection and Medline databases (from 2001 to December 2013) was conducted using as keywords “mental illness”, “mental health”, “psychiatric disability”, “mental health services”, combined with “peer support”, “mutual support”, “self-help groups”, “consumers as providers”, “peer-run services”, “peer-run programs” and “social support”. **Results:** We found 1,566 articles and the application of both the exclusion (studies with children, teenagers and elderly people; disease in comorbidity; peer support associated to physical illnesses or family members/caregivers) and the inclusion criteria (full text scientific papers, peer support or similar groups directed for schizophrenia, depression, bipolar or psychotic disorders) lead to 165 documents, where 22 were excluded due to repetition and 31 to incomplete text. We analyzed 112 documents, identifying as main peer support categories: characterization, peer supporter, practices and efficacy. **Discussion:** Despite an increasing interest about this topic, there is no consensus, suggesting realizing more studies.

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Keywords: Peer support, mental disorders, personal recovery, systematic revision.

Resumo

Contexto: O suporte interpares é um sistema de ajuda mútua baseado na crença de que alguém que enfrentou/superou adversidades pode oferecer apoio, encorajamento e orientação a outros que enfrentam situações similares. **Objetivo:** Realizar uma revisão sistemática que caracterize o suporte interpares como prática, analise a sua eficácia e caracterize os pares prestadores de suporte interpares. **Método:** Pesquisa nas bases de dados ISI Web of Science, EBSCO Psychology and Behavioral Sciences Collection e Medline (2001 a dezembro de 2013), utilizando as palavras-chave “mental illness”, “mental health”, “psychiatric disability”, “mental health services”, combinadas com “peer support”, “mutual support”, “self-help groups”, “consumers as providers”, “peer-run services”, “peer-run programs” e “social support”. **Resultados:** Encontraram-se 1.566 artigos e foram aplicados os critérios de exclusão (artigos com crianças, adolescentes e idosos; doença mental em comorbidade; suporte interpares em doenças físicas ou familiares/cuidadores) e de inclusão (revistas científicas com texto integral disponível; suporte interpares ou grupos similares dirigidos a esquizofrenia, depressão, transtorno bipolar e outras perturbações psicóticas), resultando em 165 documentos. Excluíram-se 22 por repetição e 31 por texto incompleto, resultando em 112, os quais se identificaram como principais categorias do suporte interpares: caracterização, prestador de suporte, práticas e eficácia. **Conclusão:** Existe interesse crescente pelo tema, embora alguns domínios não sejam consensuais, sugerindo necessidade de mais estudos.

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Palavras-chave: Suporte interpares, transtornos mentais, recuperação pessoal, revisão sistemática.

Introduction

Peer support is a system of mutual aid that is based on principles of respect, shared responsibility and empathic understanding of the other's situation. This understanding stems from a common experience of emotional and psychological suffering¹⁻³, based on the belief that someone who has faced and overcome some sort of adversity can offer support, encouragement, hope and guidance to others who face similar situations². Peer supporters have an empathetic understanding and can draw on shared experience when working with peers⁴.

This practice is not based on psychiatric or disease models or on diagnosis criteria that emphasize the person's symptoms and problems, but on models that value people's positive aspects of and their ability to function effectively in different contexts³. However, even though peer support is accepted and recognised in the treatment

of many conditions (e.g. addictions, cancer...), the stigma and stereotypes associated with mental illness have led people who are at an advanced stage in their recovery process to refrain from offering their contribution to the mental health system². Despite these barriers, peer support, which allows someone with an experience of mental illness to give and/or receive support from their peers, has been used and is becoming more and more a reality in the mental health system of several countries^{2,5-8}.

The literature² suggests that there are three broad categories of peer-delivered intervention: naturally occurring mutual support, participation in peer-run programmes and the use of mental health service users as providers of services and support. Mutual support is a process in which people get together voluntarily to help each other in dealing with common issues and share concerns. This is the most basic form of peer support and is provided by individuals on

a one-to-one basis and in an informal setting⁹. In peer-run groups, activities are carried out in substitution or in addition to peer support², and administration and support in these services is controlled and organised by patients, and stands as an alternative to the activities provided by traditional mental health services⁹. Both in mutual support or peer-run groups, relationships between peers must be reciprocal in nature. Although some peers may be seen as having more skills or experience than others, all participants are expected to benefit from this relationship. Lastly, with respect to peers as service providers, these are usually people with a history of mental illness who have experienced significant improvement in their psychiatric condition and, so, offer their services and/or support to others with severe mental disorders who are not yet at an advanced stage in their recovery process². This type of peer support is considered a formal therapeutic intervention, characterised by an asymmetrical relationship, in which at least one of the parties provides a service/support and the other is the beneficiary of that service/support². In this type of service, people with experience of mental illness are trained and hired to provide support for other people who resort to the traditional health services. This is the definition most commonly used in mental health literature⁹.

The effectiveness of peer support has been researched through formal interventions within health services embedded within the community¹⁰. Studies show the existence of multiple positive outcomes for people with mental illness^{6,10} and so, it plays an important role in the recovery of all stakeholders involved in this process^{10,11}. The positive effects can be grouped into three categories, depending on those who benefit from them: patients, service providers and the mental health system¹⁰. These programmes also provide a sense of connection, belonging and community, often lacking in individuals who only benefit from the services of the traditional mental health system¹².

Despite these positive effects, peer support in mental illness is still a new and unexplored subject, which generates controversy and ambiguity. This study aims to conduct a systematic review of the scientific literature in this area and presenting a model that allows the description and systematisation of the factors that characterise peer support and their effectiveness over the last twelve years.

Methods

Between 2001 and December 2013, a systematic review of the literature was performed on the scientific papers indexed in the ISI Web of Science, EBSCO Psychology and Behavioural Sciences Collection and Medline with Full Text databases. The following keywords and Boolean language search equation were used: "mental illness" or "mental health" or "psychiatric disability" and "peer support" or "mutual support" or "self-help groups" or "consumer as providers" or "peer-run services" or "peer-run programs". In Medline the following Medical Subject Headings (MeSH) were used: "mental disorders" or "mental health" or "mental health services" and "self-help groups" or "social support" or "peer support". The terms were searched as "topics" in ISI, and in "all the fields" in EBSCO. The terms selected from this research stem from the knowledge of the literature in the field. No language restriction was applied.

Articles with children, adolescents and elderly people, studies of mental illness in comorbidity with other clinical situations and peer support applied to physical disorders and/or to family members/caregivers were excluded. The studies included were those that met the following criteria: publication in scientific journals, full text available and peer support or similar groups focusing on mental illness (schizophrenia, depression, bipolar disorder and other psychotic disorders).

Titles and abstracts were reviewed by two of the authors to exclude irrelevant or ineligible papers. Each reviewer then analysed the full text of the remaining articles to decide on their eligibility. A third reviewer resolved discrepancies during a consensus discussion. A final group of eighty-two documents was obtained and analysed using NVivo 9.

The data analysis was performed by two independent investigators and validated by a third one (rater). The content analysis process, using the NVivo 9 consisted of a deductive analysis (with previous categories) whose categories and subcategories derived from the knowledge of literature in the field and translated the topics expressed in the reviewed literature. The developed model was applied to the coding of the material. The two researchers coded the material based on the hierarchy tree with the identified (sub)categories and both analysed the entire material. Record units considered were ideas (units of imprecise dimension but that allow the comprehension of the context, giving greater meaning to the record unit). The counting unit was the criteria of every time the unit (topic) appears. The coding was performed independently, thus seeking to test the robustness and the internal validity of the tool previously built. Peer agreement was calculated using Cohen's kappa (0.95), as it is considered a more robust measure than simple percentage. Cohen's kappa is a measure for assessing the reliability of categories, i.e., checking the percentage in which two researchers agree on a given number of items/categories. It is one of the most widely used measures of inter-rater agreement¹³.

Results

In total, 1,566 articles were identified and after the application of the inclusion and exclusion criteria, 165 papers remained, of which 22 were excluded due to repetition and 31 due to not including the full text. The remaining 112 documents were analysed in their entirety (Figure 1), and it was found that, despite some fluctuations,

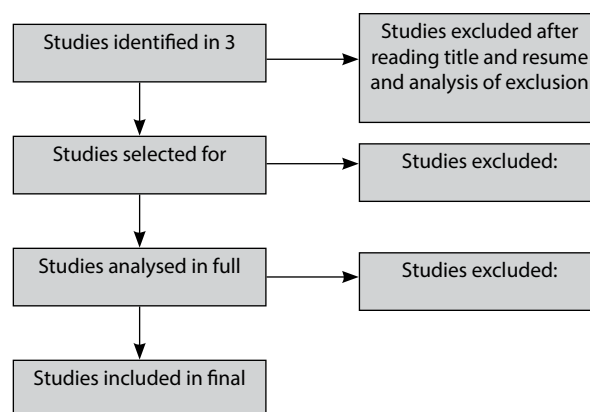


Figure 1. Flow chart showing effects of inclusionary and exclusionary criteria on final sample selection.

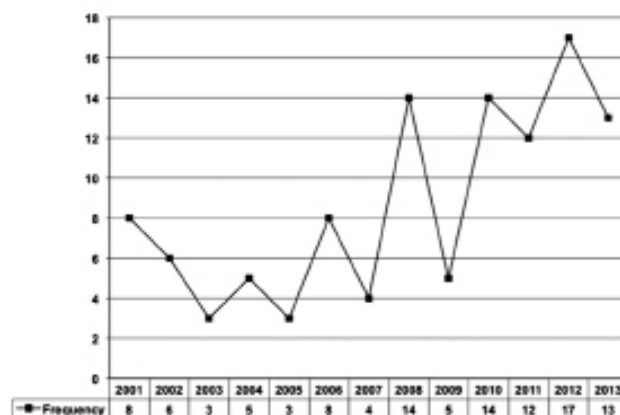


Figure 2. Number of publications in the previous twelve-year

the number of publications that meet the criteria for this review has increased over the last years (Figure 2).

Nuclear primary and secondary order categories related to peer support should be highlighted: Characterisation (Definition, Types, Objectives and Target Population); Peer Supporter (Characteristics, Selection Process, Training and Supervision); Practices (Models, Local, Contact Phase and Programmes); and Efficacy (Empirical and Theoretical Studies). The several categories were broken down into the dimensions that emerged most frequently in the literature, in some cases, reaching seventh level variables (Table 1 to Table 4).

Discussion

Despite the variations, the growing number of publications that meet the criteria of this review reveals the current interest in peer support and its relevance as a research area. The literature review resulted in a better conceptual outlining of this practice and its contribution for the personal recovery of people with experience of mental illness, as well as in a more detailed knowledge of the main limitations associated with the studies and knowledge on the subject. Taking as a starting point the four major categories that emerged (characterisation, peer supporter, practices and effectiveness), with respect to characterisation, it was found that peer support interventions are

used in a wide variety of mental illness pathologies, although it is still unusual to see those pathologies portrayed in specific studies.

As to the practices, the theory behind them is the area most explored in literature, and there is some consensus, in particular, as regards their definition and types. However, the models upon which this practice is based are mentioned only in a minority of those same studies^{22,32,42,43,54}. Similarly to what is observed in models, there is also a greater need for consensus regarding the goals of peer support, which, although becoming more and more associated with concepts like recovery and empowerment, are not yet fully defined. On the other hand, in relation to peer support programmes, it appears that, although it is advocated that they may be applicable in a variety of locations, the issues which they address, as well as the frequency and duration with which they take place, tend to vary from one organisation to another. The way these programmes are evaluated is also a gap in the knowledge concerning this topic.

With regard to the provider or peer providing the support, a consensus was found regarding the characteristics required, although its role within the organisations is still not completely defined, a fact that is pointed out in some studies as a barrier to the implementation of peer support⁴⁷. The same was observed with respect to all procedures underlying the inclusion of peer supporters

Table 1. Results to category characterization

Characterization	Results	Authors
Definition	Peer support definitions can be conceptualised into three main groups: – a system for giving and receiving help based on the principles of respect, shared responsibility and mutual aid – emotional and instrumental support, mutually offered or provided to people with similar experiences of mental illness, with the goal of producing the desired personal or social changes – a system based on the belief that people who have faced and overcome adversity can offer useful support, encouragement and hope to others who are in similar situations	Mead et al. ¹ (2001) Davidson et al. ² (2006) Grant et al. ¹⁴ (2012) Kemp and Henderson ¹⁵ (2012) Kern et al. ¹⁶ (2013) Loumpa ¹⁷ (2012) Moran et al. ¹⁸ (2013) Moran et al. ¹⁹ (2012) Moran et al. ²⁰ (2012) Repper and Watson ²¹ (2012) Solomon ²² (2004) Swarbrick ²³ (2013) Stastney ²⁴ (2012) Scott and Doughty ²⁵ (2012) Weingarten ²⁶ (2012)
Types	In literature there are different types of peer support: – mutual help group – on-line and phone support groups – peer-provided services – operationalization of peer-provided services/programmes – peer partnerships – employability of peer supporters in health services	Davidson et al. ² (2006) Moran et al. ¹⁸ (2013) Moran et al. ¹⁹ (2012) Solomon ²² (2004) Scott and Doughty ²⁵ (2012) Coniglio et al. ²⁷ (2012) DeAndrea and Anthony ²⁸ (2013) Mancini et al. ²⁹ (2013) Rabenschlag et al. ³⁰ (2012) Walker and Bryant ³¹ (2013)
Objectives	The objectives are mainly centred around the concepts of personal recovery, empowerment and advocacy, seeking to improve social functioning in daily life activities, self-esteem and self-efficacy	Brown et al. ³² (2008) Chinman et al. ³³ (2006) Corrigan et al. ³⁴ (2013) Fukui et al. ³⁵ (2010) Henderson and Kemp ³⁶ (2013) Hodges and Segal ³⁷ (2002) Ostrow and Adams ³⁸ (2012)

Table 2. Results to category peer supporter

Peer supporter	Results	Authors
Characteristics	<p>Information regarding the stage of the disease, the contractual relationship and the role of individuals in organisations is structured as follows:</p> <ul style="list-style-type: none"> – Peer supporters must suffer from the same pathology as the target population, but they must be at an advanced stage of the recovery process – In the case of mutual help or self-help groups, peer providers work on a volunteer basis, without any compensation – In the remaining types of peer support, peer supporters employees, earning a monetary remuneration – There are also some organisations where volunteer work and employment of people with experience of mental illness coexist – The service rendering scheme is generally organised in part-time shifts – The role of peer supporters is to promote group activities, provide support in daily life activities, at work and in the community with their peers. They also assist their peers in making informed decisions and developing new strategies for dealing with symptoms 	<p>Davidson et al.² (2006) Grant et al.¹⁴ (2012) Repper and Watson²¹ (2012) Solomon²² (2004) Walker and Bryant³¹ (2013) Brown et al.³² (2008) Chinman et al.³³ (2006) Chinman et al.⁴¹ (2001) Chinman et al.⁴⁷ (2008) Hodges and Hardiman⁴⁸ (2006) Lawn et al.⁴⁹ (2008) Moll et al.⁵⁰ (2009) Nestor and Galletly⁵¹ (2008)</p>
Selection process	<p>Few references were found regarding the methods and procedures to adopt or the most valued characteristics, and it is not clear who should be responsible for the selection process</p> <p>References found value the following selection criteria for this role:</p> <ul style="list-style-type: none"> – personal experience with the pathology – readiness to professional development – good social and communication skills – motivation to take on this role 	<p>Franken et al.⁹ (2010) Repper and Watson²¹ (2012) Lawn et al.⁴⁹ (2008) Moll et al.⁵⁰ (2009) Ahmed et al.⁵² (2013) Barber et al.⁵³ (2008) Dennis⁵⁴ (2003) Gillard et al.⁵⁵ (2013) Simoni and Franks⁵⁶ (2011)</p>
Training	<p>Training must be administered by health professionals and by more experienced peer supporters, although it is not clear who should be in charge.</p> <p>There is no consensual information on the methods, type and duration of the training, and we found only one article that mentions a 40-hour training programme. In general, relevance is given to topics such as:</p> <ul style="list-style-type: none"> – dealing with/sharing one's experience with mental illness – communication and group leadership skills – the educational process regarding mental illness – personal recovery, suicide prevention – definition of the role of the peer supporter 	<p>Franken et al.⁹ (2010) Bouchard et al.¹⁰ (2010) Grant et al.¹⁴ (2012) Kern et al.¹⁶ (2013) Repper and Watson²¹ (2012) Weigarten²⁶ (2012) Rabenschlag et al.³⁰ (2012) Ostrow and Adams³⁸ (2012) Chinman et al.⁴¹ (2001) Chinman et al.⁴⁷ (2008) Lawn et al.⁴⁹ (2008) Nestor and Galletly⁵¹ (2008) Gillard et al.⁵⁵ (2013) Cook et al.⁵⁷ (2010) Fukkink⁵⁸ (2011) Pickett et al.⁵⁹ (2010) Rabenschlag et al.⁶⁰ (2012) Robinson et al.⁶¹ (2010) Swarbrick et al.⁶² (2009)</p>

in organisations (process of selection, training and supervision), and information on such procedures is almost non-existent.

Lastly, from the analysis conducted on the effectiveness of peer support, it was found that several authors argue that, despite the scarce evidence and the need for further studies^{3,72}, this practice is generally considered as beneficial for customers, for peers providing the service and for the mental health system altogether^{40,44}. It was also possible to observe that efficacy studies are mainly focused on the benefits for customers and that the results they report are similar to those obtained in traditional mental health services and even better when applied concurrently. Furthermore, it was concluded that there are more empirical than theoretical studies addressing this subject,

and that the procedures, participants and instruments used in these studies vary, adjusting to the goals set by each author.

It should be noted that previous literature review studies on peer support exist^{3,44}, although infrequent or focusing only on specific areas of this subject. In this work, the structural methodology is new in this area and, in addition, it analyses peer support in a comprehensive way, attempting to portray this reality in the factors that characterise the concept, the peer supporters, the practice, and also its effectiveness. There was, thus, an attempt to find answers on the use of peer support as a mental health service for those engaged in research or clinical practice in this area, through more systematised and updated information, aiming at contributing to the

Table 3. Results to category practices

Practices	Results	Authors
Models	The models most advocated are the following: <ul style="list-style-type: none"> – Social support – Experimental knowledge – “Helper-therapy” principle – Social learning theory – Social comparison theory – Empowerment theory – Cognitive-behavioural therapy – Socio-ecological model 	Kern et al. ¹⁶ (2013) Solomon ²² (2004) Swarbrick ²³ (2013) Scott and Doughy ²⁵ (2012) Brown et al. ³² (2008) Finn et al. ⁴² (2009) Lucock et al. ⁴³ (2007) Dennis ⁵⁴ (2003) Rabenschlag et al. ⁶⁰ (2012) MacDonald-Wilson et al. ⁶⁴ (2013)
Local	Peer support can take place in several contexts: <ul style="list-style-type: none"> – In outpatient and inpatient hospital treatments – In the community: at home, at school, in prisons and in primary care centres 	Shahar et al. ⁴⁵ (2006) Dennis ⁵⁴ (2003) Robinson et al. ⁶¹ (2010) Landers and Zhou ⁶⁵ (2011) Delaney ⁶⁶ (2010) Janzen et al. ⁶⁷ (2007)
Contact Phase	This is a relatively unexplored topic, although the authors who have studied it argue that the first contact should occur early in the onset of the illness and still in inpatient treatment or immediately after discharge	Chinman et al. ⁴¹ (2001) Lawn et al. ⁴⁹ (2008) Nestor and Galletly ⁵¹ (2008) Robinson et al. ⁶¹ (2010)

Table 4. Results to category efficacy

Efficacy	Results	Authors
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implementation of a model that appears to have benefits both for people with mental illness and for the services.

Conclusion

Peer support is a practice that can significantly contribute to the recovery of individuals with personal experience of mental illness, through support provided by other people who have experienced and

overcome similar situations, by means of understanding, hope, and the sharing of strategies and guidelines. Apart from the role that the peer supporter can play in their own rehabilitation process and in that of its peers, this intervention will also improve the services provided by mental health organisations and possibly reduce costs for the very mental health system, by reducing the number of institutionalisations. The production of scientific evidence and the creation of more

specific lines of research, which demonstrate effectiveness and generate guidelines for the development and implementation of peer support programmes, may facilitate the dissemination of this practice in other countries. The results obtained in this study clearly demonstrate that this is a promising field for further research, which explore the areas of the literature listed above.

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